State Traumatic Brain Injury Advisory Board Meeting Minutes July 18, 2003

Present: Cori Fujiura, Tom Harding, Dr. Patricia Heu, Tony Hunstiger, Hal Kahikina, Kelly

Knudsen (Kauai), Rita Manriquez (Kauai)

Absent: Douglas Hupp, Mary Wilson-Isley, Malexi McPhee, Dr. Robert Sloan (Hawaii),

Lee Taylor (Maui), Kawena Young

DOH Staff: Lester Matsumoto, Aaron Sugino (Hawaii), Dan Yamada

Others: Robin Brandt, PBRRTC

I. Call to Order

Tony Hunstiger, chairman, called the meeting to order at 1:35 P.M.

II. Approval of Minutes

As no quorum was present, approval of the minutes will be put deferred until the next meeting. It was commented by a Board member that DOH (Curtis) did a good job in getting the minutes done for the STBIAB Retreat.

- III. Review of Agenda
- IV. Old Business
 - A. Speaker's Bureau Update

Tony Hunstiger reported that there was a meeting yesterday (July 17), where he and Mary talked about the budget with DOH. He is recommending to BIA of Hawaii Board of Directors that Mary Wilson-Isley be in charge of the contract to work on the financial arrangements.

Regarding the Speakers Bureau, Tony reported on behalf of Leslye Sneider, coordinator. Leslye met with Beth Freitas and the Speakers Bureau will incorporate speakers into the "Think First" K-12 Program presentations.

Tony reported that there are three types of presentations that the Speaker's Bureau offers:

- 1. A standard presentation
- 2. A standard presentation with a pediatric component
- 3. An "other" presentation with specialized aspects (medical, legal, insurance, etc.)

Tony also shared that the BIA will be having a brain injury conference in October 2003. The program committee of the BIA is looking for the Speakers Bureau to offer training to people on neighbor islands, who would come to Oahu for training then go back to their respective islands and do speaking engagements about brain injury. The BIA has a goal of speaking to 360 people a year and Tony and Mary will assist with outreach efforts to community organizations.

One point brought up was the potential benefit of the Speaker's Bureau coordinating work with DOE. Robin and Tony both mentioned being in contact with Bess Tanabe from the DOE recently. Bess has a curriculum for Special Ed. Teachers for different levels (elementary, middle and high school). Kelly shared that DOE is already doing speaking presentations and moving along with their TBI Consultation Teams. It was voiced that it would be great to have Kelly or Bess do a presentation at a future meeting of the STBIAB.

B. Traumatic Brain Injury Grant Update

Robin reported that the Distance-Learning project of the grant is almost under way. Its purpose is to provide education to professionals about Acquired Brain Injury. George Washington University's contract is almost in place. For those interested, the application is for a graduate certificate in Special Education and Brain Injury. Per Robin this is the first of its kind in the nation regarding brain injury, so we are on the leading edge of this. It will be open to 10 professionals and there are 8 scholarships being offered through the grant. The project will also need private payers to participate in it. It will be \$7500 for tuition, \$60 application fee to the George Washington University and costs for books. For those having difficulties with additional cost (e.g. books), contact Robin as she said she would try to help with other added expenses.

A teleconference will be held with Dr. Janis Ruoff from George Washington University on Friday, July 25, from 8:30 to 9:30 A.M. and Saturday, July 26, from 8:30 to 9:30 A.M. Janice will make herself available to answer question about the long-distance learning project at these times. Robin needs to know the number of people participating and would like to have DOH involved in the teleconference.

Robin also mentioned that those on the neighbor islands are encouraged to apply. She said she has 2 interested people from Maui. She asked the board members to look at the handout for more information about the project. Tony mentioned that official transcripts are needed, and Robin added that you could submit your unofficial transcripts if that is all you can get in time. Tony mentioned

that when contacting your college to have your official transcripts sent; expect to pay a fee to have this done.

Robin said she needs to know who wants to submit an application and that the deadline to let her know is July 31st. If you are mailing your application form in, make sure it is post-marked by July 31st. You can call collect or e-mail her (https://nvcwebm@lava.net) with regard to the project. Robin asked that the Board Members pass the word about the project around and that it is better to have too many people signing up rather than not enough. The coursework is targeted to start in the first week of September.

Janis will be here in Hawaii in the last week in October and a teleconference has been scheduled for October 31, from 1:30 to 4:00 pm. This is an opportunity for the STBIAB and Neurotrauma Advisory Board members to ask Janis questions about the project.

Note: George Washington University accepts no collect calls, but you can e-mail them.

There needs to be 2 members from this Board to sit on the committee to review the scholarships and make recommendations to DH for selection. These members cannot be applicants and must keep all information confidential and within the committee. Cori and Dr. Heu volunteered.

<u>Neurotrauma website</u>: Robin asked that "hits" be reported to the Advisory Board meetings, as well as Help line calls registered. It was mentioned that because members do not see changes going on, we can get discouraged and hearing that things are progressing along helps keep our hopes up. Tony said he would ask that DOH routinely share this at the meetings.

- C. Overview of the Strategic Planning Session 6/03:
 - 1. Is there a need for the facilitator to continue? Tony asked the members if they would want to ask the facilitator back to focus on what they want to do next. The topic of one discussion was whether provider issues were to be looked at from the survivor's perspective or the professional's perspective. Some comments to this issue were "having a dialog" and "both perspectives are important."

General agreement was that members present would want the facilitator to come back and help them work from broad, general and generic conceptualizations, to objectives and tasks. The Board needs to determine realistically what they can do, remembering it is advisory. There was talk of scheduling this for the next meeting or perhaps for a later meeting (after summer, perhaps when more members are back). Although the next meeting is in August, Lester mentioned he would follow-up and check as to see when Ed is available. Some members felt that probably September would be better as they would have more advance notice to insure they be available.

2. Review prioritized components of the Action Plan Objectives: Dr. Heu asked if the needs assessment done previously had addressed some of these issues. Having worked on the assessment process, Robin shared that some physicians felt there was enough care for those with brain injuries in the continuum of care, but this is not true. It was also learned that agencies did not know there were target groups (the very young and elderly) who have higher incidents of brain injuries in Hawaii. Robin also mentioned that mild TBI is a group that is not addressed or addressed very little and yet these people exist in our communities. Cori shared that as we get both professionals and survivors together, survivor's needs versus what professionals are doing ("what they are capable of providing") may come up. There was further discussion about young children, that professionals' not being aware of the skills or information needed to work with a person with TBI as well as such information not being adequately available. When asked what DDD is doing to address the five top items mentioned in the Retreat, Lester stated regarding data collection, DDD is forming a uniform data system that includes TBI, so that we would be able to store and pull out information regarding a TBI database. The system is targeted to be online in October 2003. Robin asked for a presentation by DOH on the CARES system.

Tony redirected the group back to the need to have the Board focus as a group and approach the five top items mentioned at the Retreat.

The group asked to bring back the facilitator, although there are not enough members today for a quorum to vote on this. Note: they decided to make a recommendation that the same facilitator be brought back.

Robin asked that DOH provide information on how data collection is being done in other states. Cori agreed that the group asks DOH to collect information on other registry systems and provide information to the Board.

D. Casebook of Critical Situations

Robin shared that Catholic Charities had asked assistance for one of their workers who had sustained a TBI and was experiencing difficulties with memory to follow instructions. She provided them with some information and referral to the "JAN" (Job Accommodations Network) website. http://janweb.icdi.wvu.edu/media/employmentbrainfact.doc

Tom Harding reported on an individual with TBI who was having difficulties getting accepted for SSDI payments. The members talked about asking someone for Social Security come and speak and also ask the agency what can be done for this particular case. Members would like education on other different areas beside Social Security, such as Medicaid eligibility and the benefits process. And even having a survivor speak about the gaps in services.

Cori asked that the past record of these Casebooks of Critical Situations as minutes be made available for facilitating the planning process. Tony said he would bring this subject up when we have a quorum and set up regular educational sessions as an agenda item.

E. Division Update

Aaron, Lee and Mike are in Washington D.C. right now for the TBI Grantee Meeting. Lester asked that we defer the update until Mike returns.

F. Neighbor Island TBI Activities and Community Needs Kauai people – none to report. Island of Hawaii people – none to report

G. Neurotrauma Advisory Board Updates

Tony stated there was no quorum and no decisions could be made. Instead there was an informal discussion with announcements. Minutes of the Neurotrauma Meetings are to be shared with this Board.

Robin reported on a Department of Labor Grant that focuses on youth with disabilities transitioning to adult life. It included links to school, vocation, etc.).

Tony said that the next Neurotrauma meeting is next week Friday and all STBIAB members are welcome to attend.

V. New Business

- A. For the Neurotrauma Advisory Board sub-committee on the Registry, Hal and Tom volunteered to be the STBIAB representatives. Robin suggested that if time and distance is a problem that they consider teleconferencing, conference calls, etc. to get their work done.
- B. State Traumatic Brain Injury Advisory Board sub-committees DOH asked Tony to look for 2 volunteers to be in the planning committee for the upcoming 3rd Can-Do Self-Determination Conference in October. They will need to help find local speakers and develop topics for the Neurotrauma strand. Hal and Rita volunteered.

Tony mentioned ideas for possible subcommittees that the Board may want to look at establishing: a planning committee, a registry committee and an education committee. What other committees do we want or need? Bring it up at the next August meeting.

VI. Announcements

A. Sunshine Law

Aaron had arranged to provide the revised handout copy to members (see handout); previous ones may be discarded.

B. Hal reported that a House Committee Meeting on the Protection of Children from Parental Abuse is being held on August 19, 2003, at 415 South Beretania, at

6:00 P.M. This also concerns the care of children with TBI. If you are interested contact: Mike Kahikina at 586-8465. A neighbor island meeting will also be held in Lihue, Kauai, at the King Kaumualii Elementary School, 4380 Hanamaulu Road, on August 6, 2003 at 6:00 P.M.

- C. Hal asked that the State TBI Advisory Board have a letter written that makes a statement as to its members not being paid for this service they are providing to the community. Tony will take up this matter with Hal privately.
- D. Kelly Knudsen said she will not be able to come to next meeting.
- E. Meeting adjourned at 3:14 pm.

VII. Next Meeting

Date: Wednesday, August 13, 2003 (Friday, 8/15/03 is a holiday)

Time: 1:30 p.m. to 4:00 p.m.

Sites: Capital Center VCC and Neighbor Island Sites